



Polio Survivors Serving Others

Information & Inspiration
For All Polio Survivors and Their Families

The PA Polio Network

www.polionetwork.org

November, 2023

Our Mission:

To Be in Service Providing Information to Polio Survivors, Post Polio Support Groups, Survivor's Families and their Caregivers.

Inside this Issue:

Thanksgiving – it's a time of reflection and gratitude. Honored in many different countries, Austria, Canada, China, Germany, Ghana, Grenada, Liberia, Japan, South India, Switzerland, the Netherlands, the United States and unofficially in Brazil and the Philippines. Thanksgiving has a different origin and meaning in each of these countries, but they're all celebrations of gratitude. Here in the US, we honor and thank our veterans.

The Effects of Warm Weather on Post-Polio Syndrome: In the third article in his series of Post-Polio Article Reviews, Richard Bruno, HD, PhD looks at a study completed in 2003. Although he feels that the study lacks detail, he explains that what is clear is that spending a month in a warm climate during the dead of winter significantly reduced pain, fatigue and depression in polio survivors.

The “Gentle Heroes” of the 1954 Polio Vaccine Trials: “How did we know that Jonas Salk’s polio vaccine was effective? We knew because 16 children died from polio in that study - all in the placebo group. We knew because 34 of the 36 children paralyzed by polio in that study were in the placebo group. These are the gentle heroes we leave behind.”

This powerful quote from [Paul A. Offit, MD](#), Director of the Vaccine Education Center at the Children’s Hospital of Philadelphia, brings back memories of the fear that came with the poliovirus and reminds us of our gratitude for the children and parents who were willing to participate in the vaccine trials, as Polio Pioneers.

Town Hall Conversations: We are happy to be able to bring you two new videos from Post-Polio Health International’s 2023 Educational Series. “Physical Therapy with Carolyn Da Silva, PhD, DSc” and “What Centers for Independent Living Can Do For Polio Survivors”.

World Polio Day 2023. Polio Survivors were more than willing to speak out about the miracle of the polio vaccine. Robert Camara and Diane Wall were outstanding advocates as they were published speaking out about the reality of living with the effects of the poliovirus.

Calling For Users of Negative Pressure Ventilation:

[Norma M. Braun, MD](#) is looking to interview Post-Polio patients (and others) who can describe their experiences while they were using negative pressure devices such as an Iron Lung or Chest Cuirasses. In addition, she’s hoping to interview those who may have needed ventilatory support in later years.

Dr. Braun is a pulmonologist in New York, New York and is affiliated with Mount Sinai Morningside and Mount Sinai West Hospitals. She received her medical degree from Columbia University Vagelos College of Physicians and Surgeons and has been in practice since 1982.

- Medical School - Columbia University College of Physicians & Surgeons
- Internship - Medicine & Surgery NYU/Bellevue Hospital Center
- Residency - Internal Medicine NYU/Bellevue Hospital Center
- Fellowship - Pulmonary & Critical Care Saint Luke’s-Roosevelt Hospital Center
- Certifications –
 - Pulmonary Disease
 - American Board of Internal Medicine

Dr. Braun is a Clinical Professor in the areas of Pulmonary Medicine, Sleep Medicine and Critical Care. (More Information is on Page 8).

Janice Flood Nichols Polio Pioneer



Twins Janice and Frankie,
age 6. Source: Janice Flood
Nichols

On April 26, 1954, I became one of 1,829,916 first, second, and third graders from 211 counties in forty-four states as well as children in Canada and Finland who participated in the largest vaccine trial in the history of the world. As participants in the 1954 Polio Vaccine Trial, we were dubbed “Polio Pioneers” and as such were told we were doing something not only for our generation, but also for all future generations of children.

The vaccine trial and subsequent 1954 licensure of the first polio vaccine was fraught with much scientific debate, a history of early tragic results, a need to raise sufficient funds for research via a remarkable public/private partnership, a method to facilitate issues across international borders (for example, Canada had been invaluable in supplying culture medium for mass vaccine production), the ability to find solutions to early production problems, and most importantly perhaps, the ability to convince the participating countries to find parents who would allow their innocent children to be subjected to an experimental vaccine.

But, young parents around the world were terrified of polio, a disease that never affected as many children as numerous other diseases, but had the ability to render their child (or children) healthy one day and dead or paralyzed the next, regardless of adherence to public health practices.

Even the terrifying words of radio gossip columnist Walter Winchell did not derail the trial, even though his prediction that the National Foundation of Infantile Paralysis (popularly known as the March of Dimes) had caused 150,000 children to be pulled from the trial.

Vaccine planning began in earnest in spring 1953, with a CBS radio address made by Dr. Jonas Salk and the resulting formation of the Vaccine Advisory Committee. Though there were logistical and ethical issues to resolve as well as competing opinions on vaccine trial particulars, the March of Dimes and advisors were tasked with identifying areas across the country with high rates of the disease with population centers of 50,000 to 200,000 people as this group was considered most favorable for research purposes. An infrastructure to carry out the study also had to be developed. Some southern states were ultimately disqualified because polio outbreaks had already occurred. In Canada, kindergarten children in Halifax were included because of past susceptibility to the virus, with a total of 60,000 Canadian children participating. Finnish children from 5 to 14 were included not only because of recent outbreaks but because of a personal relationship that one of the physicians had with Dr. Thomas Francis Jr. of the University of Michigan.

Dr. Francis’ group had been chosen to analyze trial results, an analysis that took a year to complete. Children were enrolled in the trial by school district. At the time, New York State was the most populous of states; as a NY native I am proud that over 400,000 NY children participated. Across the country, sixty to seventy percent of eligible children enrolled, yet in my school district 89 percent of eligible children participated. Final trial results indicated that 650,000 children received the vaccine, 750,000 children received a placebo, and 430,000 children acted as non-vaccinated control subjects.

The National Foundation declared six-year-old Randy Kerr of Fairfax, Virginia as Polio Pioneer #1. Children were injected three times, with the full series completed by the end of June. 94% of children completed the series with parents notified by mail as to whether their children were vaccinated or treated with a placebo. Placebo injected children required an additional three shot series.

No child was permitted to participate until his/her parent had completed and returned the permission form. (It was a different era as noted by the simplicity of the form, devoid of today’s copious legal disclaimers.)

continued . . .



Toddlers Frankie and Janice.
Source: Janice Flood Nichols

Yes, I was a participant but my story was a little different than that of most trial participants. In the fall of 1953 my suburb of DeWitt, NY had suffered a horrific polio epidemic. In the end, three children died, including my beautiful twin brother Frankie. I was one of two temporarily paralyzed children who made a remarkable recovery. Frankie lived less than three days after he was admitted to the hospital. I was admitted to the hospital on the night Frankie was buried and later that week my mother suffered a miscarriage. Our family's story was all too common across the globe before the polio vaccine; today's vaccine types have been expanded and perfected to meet ongoing challenges. With current understanding of scientific method, it is doubtful that I would have been allowed in the trial because I had natural immunity to one of the three Polio Types. At the time, though, local sensitivity to my family's tragedy seemed to trump other factors.

**PARENTAL REQUEST FOR PARTICIPATION OF CHILD
IN POLIOMYELITIS VACCINATION FIELD TRIAL**

The National Foundation for Infantile Paralysis, Inc., in cooperation with state and local health, medical and educational authorities, is conducting a nation-wide field study of the effectiveness of a vaccine which may be protective against paralysis due to poliomyelitis. The vaccine consists of chemically killed poliomyelitis virus of all three known types. For purposes of this study, several thousand children will be given three injections of this vaccine into the arm over a period of several weeks; at least an equal number of unvaccinated children will be observed so that a comparison can be made between the two groups. The children in each group, those who are vaccinated and those who are not, are equally important to the study. In certain instances it will be necessary to test small samples of blood at intervals during the study to determine the amount of antibodies against poliomyelitis that are present.

I HEREBY REQUEST that my child, _____, be vaccinated if selected, or otherwise be permitted to participate in the procedures described above without cost to me.

Date _____ Signed _____

Relationship to Child _____
(Must be parent or legal guardian)

School _____
(Street Address or Rural Location)

Grade _____
(City, Town or Township) (State)

NFIP Form PT-1

Permission form – Poliomyelitis Vaccination Field Trial
Source: Janice Flood Nichols

On April 12, 1955 the trial results were announced to the world: the vaccine was safe and effective! Almost immediately vaccine distribution was halted when a deadly error among some vaccine lots was discovered. The error was quickly corrected and distribution was resumed, although some communities and parents delayed distribution. One can only imagine the repercussions of such a mistake, if it was made today.



Syracuse Post Standard May 3, 1954
Photo Source: Janice Flood Nichols

This was printed in our Syracuse paper. The caption below the photo indicated that I was pensive. Sadly, when I look at the photo, I remember all too well what I was thinking: the vaccine came too late for Frankie.

In many ways, I remain that six-year-old Polio Pioneer. It has influenced my life in terms of profession and as a vaccine advocate who has written and spoken throughout the country about polio eradication. We have made so much progress yet polio is still not eradicated. Unfortunately, lowered vaccine rates even threaten developed countries including the United States, but as a survivor I must continue to speak out.

I know all too well that vaccination is our ultimate weapon! No child should remain vulnerable. – Janice Flood Nichols

Janice has done two videos for the [Vaccine Education Center](#) at the Children's Hospital of Philadelphia (CHOP).

Both are available under Survivor Stories (on our website).

The VEC is a resource for both [Adult](#) and [Pediatric](#) vaccines.



Perspectives on Covid-19 Vaccine for Kids:



I am a Polio Survivor.

Polio Pioneer Stephen Gluckman

“1952 was an epidemic year for polio, with 60,000 new cases and more than 3,000 deaths from the disease in the United States that year. Polio is a life-threatening disease that attacks the nervous and respiratory system, often resulting in paralysis, and in the 1950s children were the population most affected. However, a glimmer of hope for this epidemic was broadcasted on March 26, 1953. On a national radio show, Jonas Salk, MD, a medical researcher and virologist, announced the creation of a successfully tested polio vaccine, suggesting an end was in sight for this critical condition. And in 1954, clinical trials began on schoolchildren.”

One of those children was Stephen Gluckman. “For his participation as one of the 2 million children in the trial, Gluckman received a small piece of paper and a badge, scribed with the words “Polio Pioneer” – a memento of the occasion that his parents held on to.”

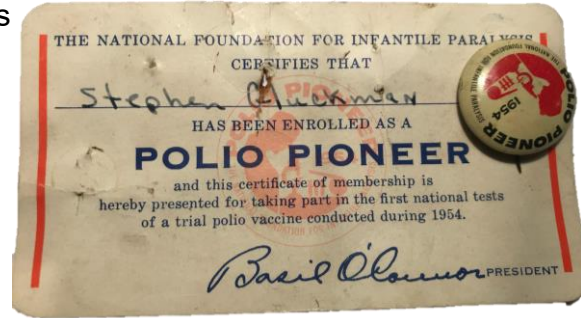
“Even though I was 7 years old, I was clearly aware of adults’ general anxiety about polio. In that time, it was a serious illness that could cause paralysis or death. Parents were cautious about kids playing together and swimming pools were closed down because of polio’s association with contaminated water. It affected everyone’s lives.

My school district was chosen to be in the Salk study. I remember my second grade class lined up, marched down to the nurse’s office, and stood outside the door. One at a time, we all went in and they took blood tests and gave us the shot. I got the placebo in the study, so I had to go back to get the vaccine when the trial ended.

There wasn’t much suspicion about vaccines in those days, so there wasn’t any resistance among parents. There was some fear among the kids, but only with the needles. There were all these 7-year-olds lined up in the hall crying. “. . . polio and the vaccine were not politicized. Polio was a common enemy.”

When I inherited a suitcase of items from my childhood that my parents collected when I was growing up, it was a surprise to see my “Polio Pioneer” badge, but a great surprise. The fact that I’m an infectious disease doctor, this historical piece is coveted by all my colleagues. I thought it was a bit strange at first that my parents held onto this, unless it reflected how important they thought this vaccine was at the time. Now, the status of polio is almost eradicated, which is amazing. Only two countries have ongoing polio and if we can get a vaccine to those areas, then polio will become extinct. There are not a lot of other candidates for diseases becoming extinct. The Salk study was one of the greatest vaccine trials there has ever been and it really was a miracle.”

[Stephen Gluckman, MD](#), now retired, was the medical director of Penn Global Medicine and a professor of Infectious Diseases at the Perelman School of Medicine.



Polio Pioneer Randy Kerr

At 9:35 a.m., April 26, 1954, six-year-old [Randy Kerr](#) of Fairfax County, Virginia, became Polio Pioneer No. 1 as the first child to be inoculated in the nationwide vaccine field trial. “I could hardly feel it,” Kerr told reporters that day. “It didn’t hurt as much as a Penicillin shot.” Administering the vaccination is Dr. Richard J. Mulvaney along with Mrs. Earl Purcell and Mrs. John S. Lucas, at the Franklin Sherman School in McLean, Virginia.



Dr. Richard Mulvaney administers the trial Polio vaccine to six-year-old Randall Kerr (Source: March of Dimes)

Polio Pioneer John Munsick



It was late summer of 1953. One day I was an active 12-year-old riding my bike, playing baseball with my friends and climbing trees on my grandmother's farm. The next day, I remember feeling bad, missing school and developing a limp. I was admitted to the hospital in Pittsburgh and placed in quarantine. My Mother and Dad stood outside my door in robes and masks, unable to come into the room. No one told me much and it was a frightening experience to be alone, laying flat on my back and not knowing what was happening.

On December 22, Dr. Franklin Neva (who was part of Jonas Salk's team), asked my parents to sign a consent form allowing me to take part in a vaccine study at the Industrial Home for Crippled Children (where I was still a patient). The study began in early 1954 and went on for a couple of months.

"I remember them coming in and giving a shot and then coming back and drawing blood a day or two later. I remember looking at my arms and noticing all the marks left by needles from the blood draws. My temperature was taken twice a day using the rectal thermometer (certainly not at all pleasant)."

Survivor [John Munsick](#)

Polio Pioneer Joe Randig

I got polio in the Fall of 1952. When the field trials started in the spring of 1954, Dr. Salk returned to the D.T. Watson Home seeking volunteers to be injected with his polio vaccine. I has been released only a few months earlier and was asked to be a part of the vaccine trial. My parents decided to volunteer our entire family (themselves included), feeling strongly that it was the right thing to do. Before we were given the polio vaccine blood was drawn to determine if we had the polio antibody in our blood. This was all done under the close supervision of Dr. Salk.

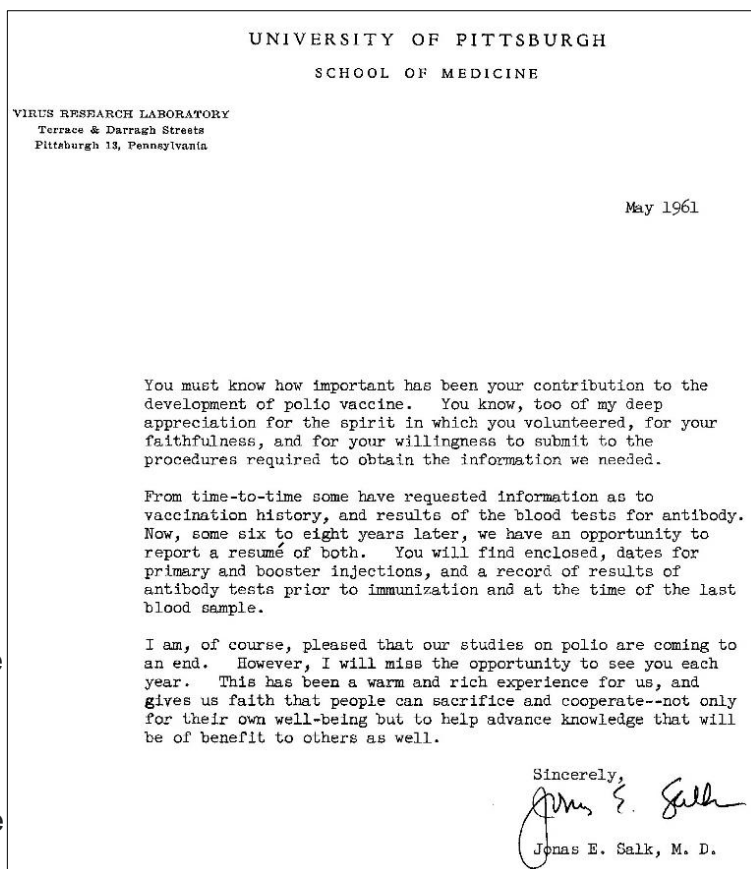
Over the spring and summer of 1954, we were injected with three doses of the polio vaccine. My parents felt strongly that we should participate in Dr. Salk's ongoing study. Through the next six years my family would make the annual 60-mile round trip from Butler to Sewickley so they could draw our blood to monitor the continued presence of the polio antibody.

Toward the end of Dr. Salk's monitoring of what became known as the "Watson Home Group," he sent out a letter of appreciation to all participants. Here are a few quotes from that letter on University of Pittsburgh School of Medicine stationery dated May 1961:

"You must know how important has been your contribution to the development of the polio vaccine. You know, too of my deep appreciation for the spirit in which you volunteered and for your willingness to submit to the procedures required to obtain the information we needed. . . It was this group that made possible the development of the polio vaccine prior to the large scale field-trials. ...I am, of course pleased that our studies on polio are coming to an end. However I will miss the opportunity to see you each year. ...It gives us faith that people can sacrifice and cooperate - not only for their own well-being but to help advance knowledge that will be of benefit to others as well."

Portions of this are from an article submitted by Joe Randig and published on August 23, 2023.

["He was just a child, but helped Dr. Salk develop the Polio Vaccine."](#)



Polio long-haulers must be their own medical advocates

By DIANNE M. WALL

Orlando Sentinel

[October 20, 2023](#)



Photo Source: [Orlando Sentinel 10/20/2023](#)

“World Polio Day is Oct. 24. I am a polio survivor, contracting polio in 1953. Most polio survivors cannot tell you who gave them the virus or exactly where they contracted it. However, I can tell you the exact time I contracted polio and how I contracted it. My mother contracted polio in 1953 in her ninth month of pregnancy carrying me.

Due to my mother’s high fever and severe symptoms of polio, labor was induced three weeks before her due date. I was delivered by the hometown doctor who followed my mother’s pregnancy from the beginning. When I was delivered, my legs, my arms, my head and neck were paralyzed.

Today’s world of medicine does not want to concentrate on the polio virus because they see no need. There are not that many of us survivors still around. I consider us the long haulers of polio. Some of us have been fortunate enough to have doctors

with knowledge of polio and its effects. I now suffer from Post-Polio Syndrome, better known as PPS. The symptoms of PPS vary in each survivor just as the polio virus did when we originally contracted it. Polio survivors who have been diagnosed with PPS live now with an ongoing decline of neuromuscular weaknesses, and sometimes failures of vital organs and body parts.

Since we polio survivors are aging, most of our doctors have either retired or are planning on retirement soon. We must be our own medical advocates who can teach our future doctors. That’s not an easy task. Medical schools do not teach much about polio in their curriculum anymore because most people in the world have been vaccinated and that is a wonderful thing. However, not everyone has been vaccinated against polio. The virus lives on without total world vaccination. Even with polio still in existence, it’s not enough to make medical school textbooks cover much of it.

My hope is that we as a society will start to discuss the importance of eradicating polio. The vaccine does work. I know that my mother wished there had been a vaccine when she was pregnant with me, but there was not. For this World Polio Day, let’s start discussions with people about a virus that still has long haulers. We are still here. Let’s not forget about an old virus. Post-Polio Syndrome usually strikes thirty to forty years after contracting the virus. We do not know what the future holds for the survivors of another virus we all know too well - COVID-19. I pray that 30 to 40 years from now the long haulers of COVID do not develop neuromuscular decline like I have and end up in a power wheelchair. Please start believing in vaccines.”

Listen to the Audio Version of this article [HERE](#)

“Dianne M. Wall lives in Winter Springs. She is the author of ‘Somebody Told Me I Could: A Polio Survivor Who’s In It For The Long Haul.’ “

Big Island survivor shares effects of post-polio syndrome

HAWAII PUBLIC RADIO | BY [CATHERINE CRUZ](#)

Published October 24, 2023



An Interview with Polio Survivor Robert "Bobby" Camara.

“To mark World Polio Day, we stop to reflect on the disease that robbed so many of the use of their limbs. The 72-year-old was recently diagnosed with post-polio syndrome, a condition marked by muscle loss and other disabling symptoms.”

"I had to come to terms with not being able to walk and that was really, really tough for somebody who was super active up until a year ago.”

"I guess the way my brain works, it's like I've got to deal with it and move on. That's kind of been my mantra."

[▶ LISTEN • 10:46](#)



Bobby Camara, right, with his sister, Linda Ann.

[Source: Hawaii Public Radio](#)



POST-POLIO ARTICLE REVIEW:

"The Effects of Warm Weather on Post-Polio Syndrome"

By [Richard L. Bruno, HD, PhD](#)

Director, International Centre for Polio Education

Question: You were the first to explain why cold makes PPS symptoms worse. You have written about medical tax deductions for polio survivors. I can't spend another winter in Michigan! Can I deduct the cost of a trip to Hawaii or even moving there?

Answer: It may warm your cold polio feet on this rainy and chilly day to know that the answer may be yes. Norwegian researchers published a study of 88 subjects diagnosed with "post-polio syndrome" (Strumse, et al. *Disability and Rehabilitation*, 2003; 25:77-84). Twenty-nine were said to be "control" subjects, even though most had "one or two physiotherapy and/or swimming sessions" each week. Fifty-nine subjects received therapy for PPS for four weeks, although the specifics of the treatment program were not spelled out. Treatment was said to be "adapted" for polio survivors from the "ordinary" rehab programs provided to non-polio survivors: "Most subjects attended daily treatment in the swimming pool and physiotherapy," classes in "relaxation techniques, self-training and gymnastics." What was done in the pool, in PT and the definitions of "self-training and gymnastics" were not provided.

And maybe it doesn't matter that we have little idea of what therapy was actually provided these polio survivors. Maybe all that matters is where the therapy was given. Thirty of the subjects were treated in Tenerife, that dry and sunny Spanish isle off the coast of Africa where the average daytime temperature was 77 degrees. Twenty-nine unlucky polio survivors were treated in their native Norway, where the daytime temperature hovers below freezing.

What a difference 45 degrees made! All subjects reported moderate pain and depression and moderate to severe fatigue before the study. The Tenerife subjects said that they "felt softer" in their muscles and joints and were more mobile and active. Pain decreased 59% in the Tenerife subjects but was reduced by only 28% in those shivering in Norway. Fatigue dropped 16% in the subjects treated on Tenerife, but actually increased by 2% in those freezing in Norway. Depression was reduced by 65% on Tenerife but only by 40% in those left behind in Norway. The authors concluded that it was "a rather positive surprise" that polio survivors treated on Tenerife felt better, and that it is important in winter "to take into account the positive psychosocial effects of some days off in warmer surroundings, using summer clothes, spending time together with fellow men and participating in the social life." (I seriously doubt that it was the "adapted" rehab program that made polio survivors feel better, but the warm, sun-soaked island, time together with fellow men and women, and a few piña coladas that did the trick.)

But, more interesting than the author's surprise at the salutary effects of a month in a tropical paradise on polio survivors, is what happened three months after the Tenerife subjects returned home. Pain and fatigue were still decreased, only by 28% and 13%, respectively, and depression was still reduced by the full 65%. But, pain and fatigue three months after treatment in those who remained in Norway actually increased by 2% and 5%, respectively, while depression edged upward to a 30% reduction. Three months after the therapy groups completed treatment, the "control" subjects (who, you'll remember, did have some unspecified "therapy" in Norway but were not in the "adapted" rehab program) had an 18% decrease in pain but a 40% reduction in depression, that is they actually felt better than those who were treated in Norway.

From my perspective, this is an invalid study that shouldn't have been published. We have no idea what therapy was given to the PPS patients and what treatment the so-called "control" subjects were actually receiving. But what *is* clear is that spending a month in a warm climate during the dead of winter significantly reduced pain, fatigue and depression in polio survivors.

What does this have to do with the IRS? Your accountant may be able to use this study to justify taking as a medical deduction a trip to warmer climates in winter as treatment for PPS. You may even be able to write off a move to a warmer state as part of PPS treatment. But, until April 15th comes around, warm your state of mind: Fill a hot water bottle, make a piña colada, sit in your most comfortable chair, close your eyes and meditate on the warmth and beauty of "palm trees . . . palm trees".

As part of their 2023 Lecture series, Post-Polio Health International has shared two interesting conversations.

[Physical Therapy](#) with Carolyn Da Silva, PhD, DSc and [Centers for Independent Living](#) with John Ballard.

[PHI](#) Director Brian Tiburzi will introduce the speaker along with their credentials at the beginning of the video.

We are happy to be able to share this series in the [Living with Post-Polio Syndrome](#) section of our website. www.polionetwork.org/living-with-post-polio-syndrome



For Users of Negative Pressure Ventilation:

(Continued from Page 1)



Dr. Norma M. Braun's plans are to include these patient experiences as part of a new book being written. This approach will be unique for medical text.

If you are interested, she wants you to know that she will protect your privacy.

NO personal information will be included.

She will do the interviews by either Phone or Zoom.

You can familiarize yourself with Dr. Braun in multiple ways.

- Her [Biography](#)
- Her Article: [Preparing for Surgery for Post-Polio or Other Chronic Respiratory Disorder Patients](#)
- Her Video with PHI: [Non-Invasive Ventilation](#)
- The [Questionnaire](#) she will be using.

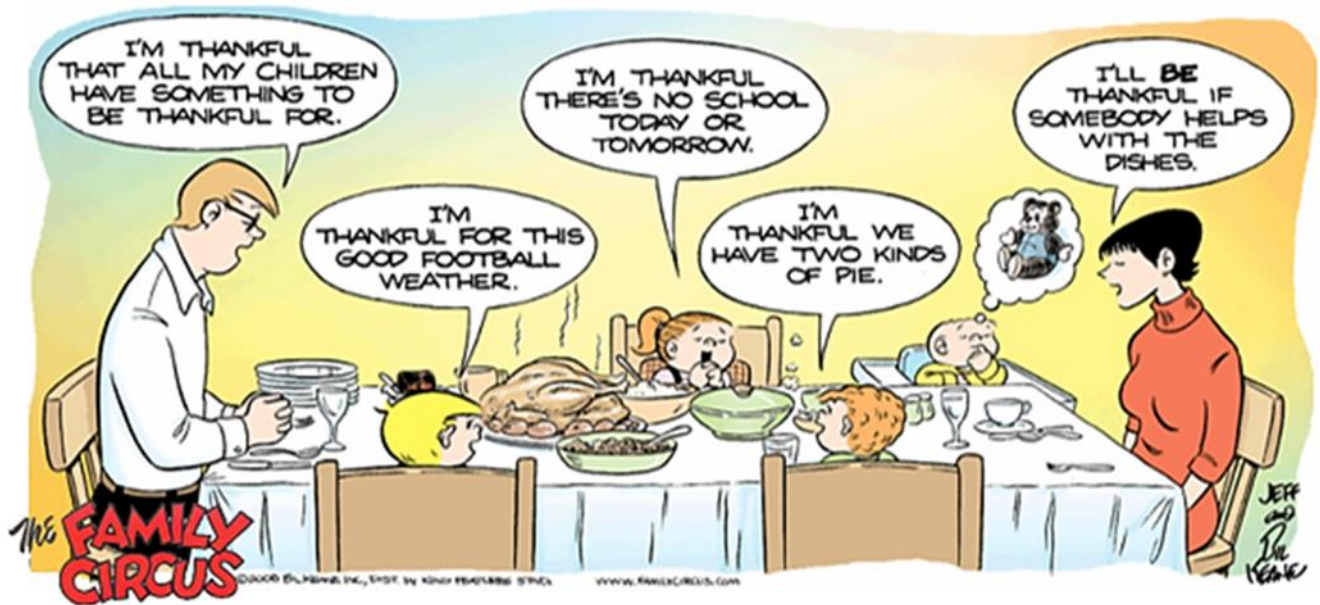
Dr. Braun's contact information: norma.braun@mountsinai.org



THANK you for your kind words, generous donations and active participation.

Your monetary [contributions](#) help our work continue.

Your [active participation](#) brings forward the questions that many, MANY polio survivors are wanting to ask.



THERE IS
Always
 SOMETHING
 BE TO
Thankful
 for.



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